

ORIGINAL

*20/"Keleen"

KELEEN LEE BURGESS MEMORIAL LECTURE

By

C. EVERETT KOOP, M.D.

SURGEON GENERAL

U.S. PUBLIC HEALTH SERVICE

AND

DEPUTY ASSISTANT SECRETARY FOR HEALTH

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES



PRESENTED TO THE ANNUAL POSTGRADUATE COURSE ON

NUTRITIONAL SUPPORT FOR THE CHILD

CHILDREN'S HOSPITAL OF PHILADELPHIA

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(GREETINGS TO HOSTS, GUESTS, FRIENDS, ETC.)

I HAVE MIXED FEELINGS ABOUT BEING HERE AND GIVING THE "KELEEN BURGESS MEMORIAL LECTURE."

OF COURSE, I FEEL VERY PROUD TO BE ASSOCIATED WITH THE MEMORY OF THE PERSON WE GOT TO KNOW ONLY A LITTLE BIT...AND FOR A LITTLE WHILE.

AND I AM HONORED BY THE INVITATION OF SO MANY RESPECTED COLLEAGUES AND FRIENDS WHO STILL THINK -- CORRECTLY OR NOT -- THAT I MIGHT YET HAVE SOMETHING OF VALUE TO CONTRIBUTE OF A MORNING HERE IN PHILADELPHIA.

BUT UNDERNEATH ALL THOSE HAPPY FEELINGS IS AN UNHAPPY ONE: I WISH SHE HADN'T HAD THE MEDICAL PROBLEMS THAT COST HER HER LIFE. I WISH KELEEN LEE BURGESS WERE STILL WITH US.

SHE'D BE GOING ON 9 YEARS OF AGE...A FOURTH-GRADER WITH TOO MANY KNEES AND ELBOWS...GIVEN TO GIGGLING AT THE DINNER TABLE...AND EXHIBITING OTHER TYPICAL 9-YEAR-OLD KINDS OF BEHAVIOR...THE KIND WE CAN'T STAND WHEN IT HAPPENS, BUT ARE FOREVER REMEMBERING WITH WET EYES FOR YEARS THEREAFTER.

BEFORE SHE WAS A MEDICAL PROBLEM AND BEFORE SHE BECAME A CLINICAL RECORD, SHE WAS A PERSON...AND A NICE PERSON AT THAT.

BUT SHE MOST CERTAINLY HAD LIFE-THREATENING MEDICAL PROBLEMS AT BIRTH.

KELEEN LEE BURGESS WAS BORN ON THE 16TH OF JULY, 1967. SHE WEIGHED 3 POUNDS, 5 OUNCES AT BIRTH AND WAS NOT ABLE TO TAKE NOURISHMENT BY MOUTH.

SHE WAS ADMITTED AS A PATIENT HERE AT CHILDREN'S HOSPITAL 2 DAYS LATER, DIAGNOSED AS HAVING MULTIPLE INTESTINAL AND COLONIC ATRESIAS. SHE PRESENTED WITH A MALROTATION OF THE COLON AND MID-GUT VOLVULUS.

THE STAFF DECIDED TO DO THE ONLY LIFE-SAVING PROCEDURE POSSIBLE, WHICH WAS AN ALMOST COMPLETE RE-SECTION OF THE SMALL BOWEL AND ELECTED TO RE-ESTABLISH THE CONTINUITY OF THE BOWEL. ONCE THAT SURGERY WAS OVER, THEY THEN HAD TO FIND A WAY TO FEED HER.

ON THE 9TH OF AUGUST A CENTRAL LINE WAS INSERTED. AND THE NEXT DAY, THE 10TH, TOTAL PARENTERAL NUTRITION WAS BEGUN. T.P.N. WAS STILL A NEW CONCEPT AT THE TIME, AND WE WERE FORTUNATE TO HAVE STAN DUDRICK AND DOUG WILMORE ON BOARD TO HELP. THERE WAS NO THOUGHT TO KEEP KELEEN ON I.V. NUTRITION ALL HER LIFE. THE HOPE WAS THAT, EVEN WITH A SHORT BOWEL, SHE WOULD EVENTUALLY BE FED ENTERALLY.

KELEEN SURVIVED THAT DIFFICULT BUT LIFE-SAVING OPERATION. IN MAY 1968, I.V. FAT WAS STARTED AND SHE CELEBRATED HER 1ST BIRTHDAY HERE AT CHILDREN'S. BUT SHE NEVER WAS ABLE TO GO HOME.

IN MAY 1969, AS SHE WAS APPROACHING HER 2ND BIRTHDAY, SHE BEGAN TO PRESENT OTHER COMPLICATIONS, DIRECTLY OR INDIRECTLY RELATED TO HER CONTINUING DIFFICULTY TAKING NOURISHMENT. WE DISCOVERED LATER THAT HER DUODENUM WAS ONLY 9 CENTIMETERS LONG AND HER JEJUNOILEUM MEASURED ONLY 6 CENTIMETERS LONG. IT WASN'T ENOUGH.

KELEEN DEVELOPED SUPPURATIVE NEPHRITIS...NODULAR CIRRHOSIS... ENTERO-COLITIS...AND ACUTE INTERSTITIAL PNEUMONIA. IN LATE MAY SHE STILL WEIGHED ONLY 11 POUNDS, 3 OUNCES. SHE WAS NOT THRIVING.

ALTHOUGH KELEEN WAS NOT MY PATIENT, I FILLED IN WHILE HER SURGEON WAS AWAY FROM THE HOSPITAL. HENCE, I HAD OCCASION TO PRESCRIBE AN ANTIBIOTIC TO CONTROL THE PNEUMONITIS. SHE DEVELOPED AN ANAPHYLACTOID REACTION. AND ON MAY 26, 1969, KELEEN LEE BURGESS DIED.

WE LEARNED A GREAT DEAL FROM THE EXPERIENCE...INFORMATION THAT HAS SUBSEQUENTLY SAVED THE LIVES OF THOUSANDS OF NEONATES IN SIMILAR OR EVEN WORSE CIRCUMSTANCES THAN KELEEN'S. AND, OF COURSE, THE APPLICATION OF T.P.N. IN ADULT MEDICINE AND SURGERY HAVE BEEN LEGION.

WE WERE, OF COURSE, CRITICIZED AT THE TIME FOR TRYING TO SAVE HER LIFE. IT WAS TOO COSTLY...SHE WOULD NEVER LEAD A NORMAL LIFE ANYWAY ...WE WERE GOING AGAINST NATURE..."PLAYING GOD"...AND SO FORTH.

BUT WE HAD THE SUPPORT AND UNDERSTANDING OF KELEEN'S PARENTS, WHO BELIEVED -- AS WE DID -- THAT KELEEN DESERVED ALL THE LIFE TO WHICH SHE WAS ENTITLED. AND WE HAD THE MORAL AND ETHICAL OBLIGATION TO HELP HER LIVE.

ALL THAT HAPPENED MANY YEARS AGO. BUT THE ISSUES AND QUESTIONS PRESENT THEN ARE PRESENT NOW. THEY ARE UNIVERSAL QUESTIONS AND THEY DON'T GO AWAY.

I CAN VOUCH FOR THAT, REMEMBERING THOSE DAYS VERY WELL. AND NOW, AS SURGEON GENERAL, I'VE HAD TO DEAL WITH THOSE ISSUES AND QUESTIONS NOT JUST FOR THE SAKE OF ONE CHILD -- ONE "BABY DOE," AS IT HAPPENED -- BUT FOR ALL BABIES EVERYWHERE.

THE ISSUES RE-SURFACED IN APRIL OF 1982, WHEN A LITTLE BOY WAS BORN IN BLOOMINGTON, INDIANA, WITH ESOPHAGEAL ATRESIA AND DOWN SYNDROME. HIS PARENTS, ACTING ON THE ADVICE OF THEIR PHYSICIAN, ASKED THAT THEIR SON BE GIVEN NO WATER, FOOD, OR MEDICAL TREATMENT OF ANY KIND.

IN AN UNUSUAL MOVE, A GROUP OF HOSPITAL PHYSICIANS SUED TO FORCE THE PARENTS TO CHANGE THEIR MINDS AND ALLOW THE SURGERY TO BE PERFORMED. THE LAW THEY USED WAS THE INDIANA STATE LAW AGAINST CHILD ABUSE AND NEGLECT.

IN ONE OF THE MOST UNUSUAL DECISIONS IN AMERICAN LEGAL HISTORY, THE INDIANA STATE SUPREME COURT RULED IN THE PARENTS' FAVOR, ALLOWING THIS "MERCY KILLING" TO PROCEED.

THAT DECISION WAS APPEALED TO THE U.S. SUPREME COURT. BUT BEFORE ANYONE COULD ACT, "BABY DOE" DIED AND THE WHOLE QUESTION WAS MOOT.

AT LEAST IT WAS MOOT AS FAR AS THE COURTS WERE CONCERNED. BUT NOT AS FAR AS MEDICINE AND PUBLIC POLICY WERE CONCERNED.

FOR THE NEXT THREE YEARS THE DEBATE CONTINUED. OUR DEPARTMENT PROPOSED NEW REGULATIONS UNDER THE CIVIL RIGHTS ACT...WE WERE TAKEN TO COURT BY SEVERAL MEDICAL ASSOCIATIONS...NEW CHILD ABUSE LEGISLATION WAS PROPOSED, DEALING SPECIFICALLY WITH SITUATIONS LIKE THE ONE IN BLOOMINGTON...IT WAS PASSED BY THE CONGRESS...AND FINALLY, ON APRIL 15, 1985, THE THIRD ANNIVERSARY OF THE DEATH OF "BABY DOE," WE PUBLISHED THE SO-CALLED "BABY DOE" REGULATIONS THAT ARE IN EFFECT TODAY.

I'D LIKE TO SAY THAT -- FOR THE TIME BEING, AT ANY RATE -- THE CASE IS CLOSED. BUT UNHAPPILY THAT'S NOT TRUE. HOWEVER, LET ME FIRST CLARIFY WHAT THE "BABY DOE" ISSUE WAS ALL ABOUT.

IT WAS ABOUT A PATIENT'S RIGHT TO WATER AND NUTRITION...NOTHING LESS THAN THE ISSUE WE FACED ALMOST 9 YEARS AGO, WHEN KELEEN BURGESS WAS CHECKED IN HERE AT CHILDREN'S HOSPITAL.

A HOSPITAL PATIENT -- OF ANY AGE -- HAS A RIGHT TO FOOD, WATER, A BED, AND A BLANKET. THAT'S THE MINIMUM. YOU HAVE THE OBLIGATION TO NOURISH A PATIENT, IF AT ALL POSSIBLE, AND TO MAKE THE PATIENT AS COMFORTABLE AS POSSIBLE.

I NEVER THOUGHT THAT ANYONE WOULD EVER ARGUE ABOUT SUCH AN IRREDUCIBLE MINIMUM IN HEALTH CARE. BUT WE'VE HAD ARGUMENTS...AND THE PEOPLE INVOLVED HAVE BEEN PHYSICIANS AND HOSPITAL ADMINISTRATORS.

THE LAW AND THE REGULATIONS SPELL OUT IN LEGAL LANGUAGE WHAT WE DID ON INSTINCT 9 YEARS AGO. LET ME QUOTE FROM OUR REGULATIONS, WHICH, FOR THE MOST PART, ARE TAKEN VERBATIM FROM THE LAW ITSELF.

FIRST OF ALL, THE REGULATIONS TALK ABOUT THE -- QUOTE -- "BASIC PRINCIPLE THAT ALL DISABLED INFANTS WITH LIFE-THREATENING CONDITIONS MUST BE GIVEN MEDICALLY INDICATED TREATMENT" -- CLOSE QUOTE.

THE LAW DOES NOT SAY "SHOULD BE GIVEN" OR "MIGHT BE GIVEN" OR "OUGHT TO BE GIVEN." THE LAW SAYS "MUST BE GIVEN." IN THIS PART OF THE LAW, THERE IS NO ROOM FOR SUBJECTIVE DECISION-MAKING. YOU DO IT ...PERIOD.

BUT JUST WHAT DO WE MEAN BY "MEDICALLY INDICATED TREATMENT"?

THAT QUESTION REALLY BOTHERS ME. IT REMINDS ME OF THE THAT OLD STORY ABOUT THE MAN WHO WENT INTO THE FERRARI SHOWROOM, LOOKED AT A CAR, AND ASKED THE SALESMAN HOW MUCH IT COST. AND THE SALESMAN REPLIED, "SIR, IF YOU HAVE TO ASK, YOU CAN'T AFFORD IT."

SO...IF YOU HAVE TO ASK WHAT IS "MEDICALLY INDICATED TREATMENT," YOU PROBABLY CAN'T AFFORD TO STAY IN MEDICINE. BUT...THAT'S A MINORITY VIEW, I KNOW, SO LET'S KEEP GOING.

AND ANYWAY, SOME PHYSICIANS DID ASK THE GOVERNMENT, "WHAT DO YOU MEAN BY THAT?" AND WE HAD TO COME UP WITH AN ANSWER THEY COULD UNDERSTAND.

"MEDICALLY INDICATED TREATMENT," WE SAY IN THE REGULATIONS, IS -- QUOTE -- "DEFINED IN TERMS OF ACTION TO RESPOND TO THE INFANT'S LIFE-THREATENING CONDITIONS BY PROVIDING TREATMENT (INCLUDING APPROPRIATE NUTRITION, HYDRATION, OR MEDICATION) WHICH, IN THE TREATING PHYSICIAN'S...REASONABLE MEDICAL JUDGMENT WILL BE MOST LIKELY TO BE EFFECTIVE IN AMELIORATING OR CORRECTING ALL SUCH CONDITIONS." CLOSE QUOTE.

CLEAR ENOUGH? NOT REALLY. PHYSICIANS KNOW THAT THERE ARE SOME SITUATIONS IN WHICH "TREATMENT" SIMPLY IS NOT "MEDICALLY INDICATED." AND JUST IN CASE YOU MISSED THAT LECTURE IN MEDICAL SCHOOL, WE HAVE HELPFULLY SPELLED IT ALL OUT IN THOSE VERY SAME REGULATIONS...SECTION 1340.15 (B) (2) OF THE 45TH CHAPTER OF THE CODE OF FEDERAL REGULATIONS, TO BE EXACT.

THERE IS ONE ADDITIONAL ELEMENT. WHEN CONGRESS USED THE WORD "TREATMENT" IN THE LAW, THEY MEANT IT TO INCLUDE "APPROPRIATE NUTRITION, HYDRATION, OR MEDICATION" AND WROTE THOSE TERMS INTO THE LAW SO THAT THERE WOULD BE NO CONFUSION ABOUT IT. IN OTHER WORDS, THE CONGRESS SPECIFICALLY INTENDED THAT PATIENTS -- IN THIS CASE, INFANT PATIENTS -- SHOULD NOT BE STARVED TO DEATH NO MATTER WHAT THE PROGNOSIS.

TREATMENT IS NOT "MEDICALLY INDICATED" WHEN...

- * "THE INFANT IS CHRONICALLY AND IRREVERSIBLY COMATOSE...
- * OR WHEN..."THE PROVISION OF SUCH TREATMENT WOULD MERELY PROLONG DYING, NOT BE EFFECTIVE IN AMELIORATING OR CORRECTING ALL OF THE INFANT'S LIFE-THREATENING CONDITIONS, OR OTHERWISE BE FUTILE IN TERMS OF THE SURVIVAL OF THE INFANT..."
- * OR WHEN..."THE PROVISION OF SUCH TREATMENT WOULD BE VIRTUALLY FUTILE IN TERMS OF SURVIVAL OF THE INFANT AND THE TREATMENT ITSELF UNDER SUCH CIRCUMSTANCES WOULD BE INHUMANE."

IN OTHER WORDS, THE LAW WILL ACCEPT A DOCTOR'S JUDGMENT ON WHAT IS MEDICALLY INDICATED TREATMENT OF A BABY, IF THE BABY IS CHRONICALLY OR IRREVERSIBLY COMATOSE...IF TREATMENT WOULD JUST PROLONG THE ACT OF DYING ...OR IF TREATMENT ITSELF WOULD BE INHUMANE.

CLEAR ENOUGH? NO, NOT YET.

THE GOVERNMENT WAS CONCERNED THAT SOME PHYSICIANS MIGHT STILL LOOK FOR A LOOP-HOLE IN THIS MATTER AND SO THE CONGRESS WENT AHEAD AND PLUGGED IT. THE REGULATIONS ARE QUITE CLEAR BY ADDING THAT "EVEN WHEN"..."EVEN WHEN ONE OF THESE CIRCUMSTANCES IS PRESENT" AND A PHYSICIAN DECIDES TO WITHHOLD MEDICALLY INDICATED TREATMENT...EVEN THEN -- QUOTE -- "THE INFANT MUST NONETHELESS BE PROVIDED WITH APPROPRIATE NUTRITION, HYDRATION, AND MEDICATION."

LET'S SAY, FOR EXAMPLE, THAT YOU ARE PRESENTED WITH AN INFANT WHO IS HOPELESS...NOTHING CAN BE DONE TO SAVE THAT CHILD...NOTHING MEDICALLY INDICATED...AND NOTHING NON-MEDICALLY INDICATED...NOTHING.

WHAT DO YOU DO UNDER THE LAW?

YOU TRY TO FEED THAT CHILD SOMEHOW. YOU'RE LEGALLY AND ETHICALLY OBLIGATED TO TRY.

AND YOU TRY TO GIVE THAT CHILD SOME LIQUIDS. YOU HAVE TO TRY, UNDER CURRENT LAW AND CERTAINLY UNDER THE CODE OF MEDICAL ETHICS, WHICH PRE-DATES BY A GOOD MANY YEARS 45 C.F.R. 1340.15 AND SO ON.

IN OTHER WORDS, WHAT WE TRIED TO DO -- AND DID DO -- FOR KELEEN BURGESS BACK IN 1967 IS NOW THE LAW.

AT THIS POINT, LET ME OFFER A FINAL OBSERVATION AND THEN I'LL BE HAPPY TO TAKE YOUR QUESTIONS.

THE MEDICAL PROFESSION -- FOR GOOD OR ILL -- HAS ENORMOUS POWER AND PRESTIGE IN OUR SOCIETY. DOCTORS HAVE BEEN HELD IN AWE. WE ARE OFTEN SEEN AS A KIND OF DEMI-GOD.

IT'S EMBARRASSING TO TALK ABOUT IT. YET, I THINK IT'S TRUE.

HOW DID WE ATTAIN SUCH PRE-EMINENCE? WHY ARE WE CONSIDERED TO BE GOD-LIKE? WHAT'S THE ANSWER TO THAT?

THE ANSWER IS NOT HARD TO GIVE. WE'VE ALWAYS SAVED LIVES. PEOPLE HAVE COME TO DOCTORS FOR LIFE -- FOR THEIR OWN LIVES OR FOR THE LIVES OF PEOPLE THEY LOVE.

WE'VE ALWAYS ADVERTISED OURSELVES AS DOING THAT KIND OF WORK... SAVING LIVES.

THE GOOD LORD GIVETH AND THE GOOD LORD TAKETH AWAY. BUT MANY PEOPLE THINK WE HAVE THE POWER OF THE GOOD LORD...AND TO SOME EXTENT MAYBE WE DO. BUT IT IS THE POWER TO GIVE, NOT TO TAKE AWAY. WE DON'T HAVE THE POWER -- AND WE CERTAINLY DON'T HAVE THE RIGHT -- TO TAKE LIFE AWAY.

KELEEN BURGESS WANTED TO LIVE. SHE COULDN'T TALK ABOUT IT AND SHE OBVIOUSLY COULDN'T WRITE ABOUT IT. BUT YOU COULD TELL. FOR 20 MONTHS SHE STAYED WITH US, INSTINCTIVELY FIGHTING TO STAY ALIVE UNTIL SHE FINALLY LOST HER BATTLE AGAINST OVERWHELMING ODDS OF DISEASE AND DEBILITATION.

BUT HER MEMORY IS VERY IMPORTANT TO US. HER STRUGGLE FOR LIFE PERMITTED US TO LEARN MANY NEW THINGS ABOUT THE TECHNOLOGY OF TOTAL PARENTERAL NUTRITION. SHE GAVE US THAT AND IT TURNED OUT TO BE A PROFOUNDLY GENEROUS GIFT FROM SO SMALL A CHILD.

BUT HER MEMORY IS ALSO IMPORTANT BECAUSE IT REMINDS US ONCE AGAIN
OF JUST WHAT IT IS WE DO HERE IN THIS HOSPITAL AND IN HOSPITALS ALL
ACROSS THIS COUNTRY.

WE SAVE LIVES. WE DON'T TAKE THEM.

THANK YOU.

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